

Appendix VII

Samples of Research Data

- 1) "Families", a Report of the House Memorial 5, Task Force on Young Children and Families (1990, New Mexico)
- 2) Parent Involvement: The Opportunity of the Decade, The Special Edge, Resources in Special Education
- 3) Families and Disability Newsletter, The University of Kansas, Beach Center on Families and Disability

"Families

*are big, small, extended, nuclear, multi-generational,
with one parent, two parents, and grandparents.*

*We live under one roof, or many. A family can be as
temporary as a few weeks, or as permanent as forever.*

*We become a part of a family by birth, adoption,
marriage, or from a desire for mutual support ...*

*A family is a culture unto itself, with different values
and unique ways of realizing its dreams; together our
families become the source of our rich cultural heritage
and spiritual diversity ... Our families create
neighborhoods, communities, states, and nations."*

Report of the House Memorial 5
Task Force on Young Children and Families (1990, New Mexico)

THE Special Edge

Resources in Special Education
A Special Project of the California Department of Education with California State University, Sacramento

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PARENTAL INVOLVEMENT: THE OPPORTUNITY OF THE DECADE

by Sonya Steiner

"The opportunity for parent involvement in the education of their children is much larger than improving student achievement. It is central to our democracy that parents and citizens participate in the governing of public institutions. Parent involvement is fundamental to a healthy system of public education." California State Board of Education, *Policy on Parental Involvement in the Education of Their Children*, 1994.

Family involvement in the education of their children is the opportunity of this decade. To facilitate parental involvement in the education process, a number of laws and initiatives have included a strong mandatory parental component. The Individuals with Disabilities Education Act (IDEA), Improving America's Schools Act (IASA) and the Challenge District Initiative have given a clear message of the intent to involve families of children with special needs in all aspects of education. The California State Board of Education has adopted a strong policy reflecting the importance of family involvement.

Even with this strong emphasis on parental involvement and participation, there are still many families that are not involved with the process. It is recognized that schools alone cannot educate the child. Parents, families, and communities are needed to work with the schools to provide effective educational programs. Conversely, with the many changes in the family structure and society in general, it is recognized that parents cannot educate their children alone. Henderson, 1991, reviewed forty-nine research studies from which she concludes, "so long as parents are the basic ingredient of the improvement strategy, students do better in school." She further notes, while parental involvement is effective, only ten percent of the parents participate in the education of their children through organized parent/school activities.

Lack of Parental Participation

Why are so few parents participating in their child's education at school? Many schools have established a number of programs to reach parents. Economic shifts have caused schools-families-communities to go into a survival mode where each is struggling to maximize shrinking

dollars. While the societal factors affecting economics have been major, the changes in the family structure have had a dominant affect as well. Adjusting to the tremendous changes occurring in families over the last twenty-five years has created a major shift in how schools and families work together.

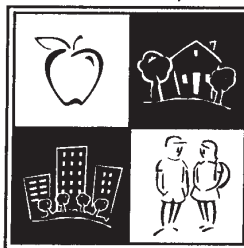
What are the major shifts in society that have affected our family structure? As schools develop parental involvement plans what considerations should they take into account?

Recent surveys found the following (Edge and Davies, 1994):

1. Structure: The family structure has undergone several dramatic changes. Sixty percent of today's children will live with a single parent at some time in their life before they reach the age of eighteen.
2. Work place: Changes in the work place show eighty percent of children under the age of eighteen have working mothers.
3. Financial: Economic status is decreasing with twenty percent of our children, under the age of eighteen, classified as poor; ninety-one percent of families have no health insurance.
4. Childcare: With the single parent or both parents working outside of the home, finding adequate child care is a challenge.
5. Time: Single mothers and single fathers feel they have little time to help their children or participate in school activities during the school day.
6. Value of Participation: Some parents say they do not feel comfortable at school.
7. Skills: Some parents do not know what to do to help their children at school. They do want to help their children and they do want their children to do well in school. Parents may lack the skills to teach their children, but those skills are teachable.

It must be kept in mind that families are not a homogeneous group. There is a need for services and programs to be individualized both in type and level of activities. With the changing status of the family, the partnership between family-school-community will need to expand. ■

School • Community • Home



Partnerships



Families and Disability Newsletter

Volume 9 Number 1

Summer 1998

Strengthening Families

Since our beginning ten years ago, we at the Beach Center have sought to find ways for families to make their lives better and have more control over their lives. This empowerment process starts with families and service providers sharing responsibility and having a mutual understanding.

These two simple practices can move mountains. As one of our research participants said: "Parents don't necessarily have to have their fingers in everything and be trying to change the whole system. They can advocate for their child in their way. Empowerment doesn't have to be huge and visible."

Families do have to work within systems, and when we researched service programs, we found that supportive programs are those that are upbeat, non-judgmental, and geographically and emotionally accessible.

In that survey of 350 parents who have children with disabilities at 65 family support programs, we received lots of answers about how programs' skill-building opportunities, services, and information-sharing strengthen families. Overall, we found that programs that really knew the "ins and outs" of

the whole service system network, formed responsive partnerships with families, and fostered a sense of community were the ones in which families could strengthen their wings and fly.

As we keep examining family strength, we find that vaulting over

***Harambee is the
Swahili word that
means "Let's pull
together"***

life's challenges is much easier in an encouraging environment.

Harambee, Swahili for "Let's pull together," is a reminder that programs can't be empowering unless they have support and operate in responsive environments.

That support typically comes from legislative bodies, policy makers, agencies, community members, funding sources, and a community working toward more inclusive practices. At national and state levels, policies and practices influence how key resources such as health care, education, and social service systems do their part to enrich the lives of families who

have children with disabilities.

Janet Vohs, in the book that came from our national conference (*Cognitive Coping, Families, and Disability*, Brookes), used a metaphor that depicts the long-term effects of an enriched environment: European castles and homes, Vohs wrote, once had a small room set aside for making bread. In those same rooms today, cooks don't have to use yeast, because the yeast culture lives in the air causing any dough to rise on its own.

An environment that lifts families instead of dragging them down is the one the Beach Center envisions. As we work toward that goal, we continue to learn from family stories. Many are about not giving up, clearing a path, traveling alone, or letting go. As you read the following stories (and our related research), we hope you find at least one story that resonates for you.

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Family/Professional Collaboration Promotes a Relationship in Which Family Members and Professionals Work Together to Ensure the Best Services for the Child and the Family.

PRINCIPLE

I

In order to ensure the best services for the child and family, families and professionals need to develop a relationship within which they can work together. This working together aspect of the relationship cannot be taken for granted, but must be intentionally and carefully built and nurtured by professionals and families alike.

Collaborative relationships might be compared to team building. A team develops through time spent together—learning each other's strengths and abilities, learning when to give and when to stand back. If we are able to develop a strong team committed to working on behalf of my child and family, I believe we will experience better outcomes.
(K. Witkin, Parent)

The notion of working together may seem too obvious to elaborate upon; yet, too often, when the families of children with special health needs seek services and become involved in relationships with providers, they become the recipients of the services, rather than partners in the design, implementation, and evaluation of the services. If families and professionals are striving to work collaboratively, no longer can professionals do something to families. We must be engaged as partners.

Our attitudes really make a difference in our relationships. As professionals, we must relate to parents as equal partners, and we have to be comfortable in our role as consultants to the parents, recognizing that they are ultimately responsible for making the major decisions regarding the care of their children. It is important to respect each other, including our differences, and recognize each other's values. We must have compassion for each other as well as the children.

(S. Handmaker, Professional)

When family members and professionals work together to develop and ensure the best services for children and families, they demonstrate a shift in philosophy, a new way of relating to each other. They become partners, sharing the responsibility, the fears, the joy, the satisfaction that comes from working in partnership. Does anyone give up power and control? Perhaps! Does anyone compromise? Perhaps! But does the bottom line, doing what makes sense for the child and family, ever change? No. As long as everyone involved—child, family, professionals—understands and shares that common goal, then the flexibility and liquidity critical to any relationship can work its magic.





How do such relationships develop? We believe that, even in the context of a traditional system of health care, opportunities arise for parents and professionals to interact in ways that, slowly perhaps, interrupt old patterns, connect with new ideas, and communicate a mutuality of interest.

*(C. Hassler, Professional, and
N. DiVenere, Parent)*

Families who have children with special health needs engage in many relationships with professionals over a long period of time. Therefore, it is important for administrators and supervisors to understand that the development of a collaborative relationship takes time and may appear to be less efficient in the short run. Working together initially may consume considerable time and energy as the elements of collaboration, such as developing trust and demonstrating a respect for cultural traditions, are worked out. In the long run, however, energy and dollars invested in collaborative relationships will not only contribute to ensuring the best services for children and families, but will also support the work of the professional partner.

Our kids are not very likely to be cured, so we really want long-term, productive relationships.

(B. Anderson, Parent)

PRACTICE EXAMPLES

FAMILY

When we brought Elsie home from the hospital, there were ongoing issues of concern. One of these issues had to do with her nutrition and the balance of some basic elements in her body. When I asked my pediatrician about it, he said: "I'm not sure what I'm looking for; who should I call to find out?" It was wonderful. I referred him to one of her physicians from the hospital and I was all set. He didn't question the issue I raised and he was honest in response. I felt like we were working with Elsie together. (Megan Sutton, Parent to Parent of Vermont, Middlebury, Vermont, 802 545-2475)

COMMUNITY

Un Buen Comienzo/A Good Beginning (UBC) offers daycare and therapeutic services to young children with special needs and their families. This program is part of the Rosemount Center, a bilingual and multicultural daycare which encourages peer interaction and socialization among all children of various ages ranging from four weeks through five years. The developmental curriculum is enriched by the intertwining of multicultural and bilingual components. In our view, partnerships with team members involved in program planning for children enrolled in our program are as important as the work accomplished through the services we provide; of course the family is placed at the head of this team when it comes to decision-making and advocacy issues. We always assume that the family knows what is best for their child and will advocate for him/her in all situations. Many Hispanic families in our program have recently immigrated to the United States and are not fluent in English.

Family/Professional Collaboration Recognizes and Respects the Knowledge, Skills and Experience that Families and Professionals Bring to the Relationship



Families and professionals bring essential knowledge, skills, and experience to a collaborative relationship. In the past, families were often considered the receivers of professional expertise, without acknowledgement of the unique and valuable contribution they make. The collaborative model recognizes the expertise of all the people involved in caring for a child with special health needs.

Professionals and consumers can often both be considered experts. In genetics, as in many other fields, a consumer's life experience and knowledge are essential to making good use of the scientific information and clinical experience of the professional. Now more than ever, there is a need to foster a partnership between professionals and consumers and break down barriers to communication.

(J. Mackla, Parent)

With their knowledge regarding certain aspects of a child's condition, professionals at times may lose sight of the fact that the family is the center and the constant in the child's world, whereas professionals move in and out of the various service systems. The family is intimately familiar with the strengths and abilities of the child, the challenges of providing care and the needs of others in the family. This knowledge is critical to the success of any health care plan.

For a number of years, the attitudes of professionals working with families have seemed to say, "Tell us what your problem is and we'll fix it." The professionals were in a sense in control. We professionals need to change our orientation. We need to reframe that question to ask simply "How can we help you?" We need to begin to view our work with families as a partnership in which we are the consultants but the families are in charge, and it is on the care of their child that we are in fact consulting them.

(K. Barnard, Professional)

Each member of the team, family member or professional, brings an expert body of knowledge, skills, and experience to the relationship. Whether in a team meeting, during a home visit, at a doctor's office, or in a school setting, everyone must be encouraged and have an opportunity to express opinions and work together. It is impossible to develop a plan that ensures the best services for the child and the family without participation from all members of the team.

Collaboration and being a part of it all has enabled us (and others) to model for our daughter Cassilly how to problem solve—that everyone's point of view needs to be listened to and respected—that her "solutions" are valued (and often have been the ones selected). I guess that she, in increasing ways as she got older, has had not only choices but she shared in the responsibility of ensuring the best results.

(J. Woll, Parent)

Building on the experience of families and professionals who have worked together on issues related to a specific child is an excellent basis for work in the program and policy arena.

Collaboration has proven to be an exciting and powerful model for effecting national policy. I think the direct, honest realism families share with federal agencies makes it imperative we respond. We cannot use bureaucratic gameplaying and regulatory barriers to avoid action. It may be as dramatic as a family who helps change policy by appealing to the U.S. President to waive regulations which prevent them from taking their child home from the hospital or as subtle as the quiet, effective presence of families on the Federal Interagency Coordinating Council.
(M. McPherson, Professional)

Such opportunities for collaboration to improve programs and policies exist at the community, state, and national levels. Families and professionals can pool their knowledge, skills, and experience to initiate changes that reflect a family-centered approach to services.

PRACTICE EXAMPLES

FAMILY

It was in July, 1991, that I asked to see my daughter Bridgett's records while she was being cared for on the Pediatric Unit. Permission denied! How was I expected to care for my daughter on the weekend without knowing in detail about her care the previous five days? Was her new antibiotic started? Had she stopped vomiting and if so, when? Was her food staying down better? Four months later, after a series of letters explaining the need for parents to have access to their child's records,

the pediatric facility conducted a training, changed their policy and now encourage parents to read and write notes in their child's records.
(Maureen Mitchell, Regional Coordinator, Vermont Parent to Parent, Pownal, Vermont, 802 823-5256)

GRANDPARENTS

Grandparents can lend a type of strength and support to family members that no other generation can, just through their own experience and wisdom.
(J. Ratner, PACER Center)

In an effort to reach an underserved population that also is challenged by the birth of a child with a disability, a Grandparent-to-Grandparent program is being piloted through the PACER Center. The program goals are to:

- allow grandparents of children with special needs to share their concerns, joy, and interests with other grandparents;
- teach grandparents helpful strategies to support their children and families while caring for themselves;
- inform grandparents about programs and services available for children with disabilities and families;
- support, inform, and empower grandparents in assisting their children and grandchildren.

Grandparents will be trained to lead the support group and will expand a phone-support network for other grandparents. The idea behind the program is to have grandparents serve as their own best resources. (Jamie Smith and Paula Goldberg, Co-Director, PACER Center, Inc., Minneapolis, Minnesota, 612 827-2966)

